The other care crisis: Making social care funding work for disabled adults in England
Acknowledgements

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Modelling: © Scope, PSSRU at LSE 2013

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In the summer of 2012 over 600 disabled adults aged between 18 and 64 took part in our survey and told us about their experiences of care and support in England. All quotes in the report come from the survey and the conversations we have had with people afterwards.

Some of the statistics used in this report are based on estimates modelled by the Personal Social Services Research Unit (PSSRU) at the London School of Economics and Political Science (LSE). For the full details underpinning our estimates of the scale and cost of different eligibility levels see the accompanying technical report. It is available at www.scope.org.uk/othercarecrisis
Over 105,000 disabled people risk losing out on vital care and support.

105,000

Since 2008 the number of people using care has fallen by at least 90,000, or one in six of all people using care.

90,000

This is exacerbated by funding cuts – by 2015 council budgets will have shrunk by 28%.

28%

Social care for working age disabled adults is under-funded by at least £1.2 billion.

£1.2 billion

40% of disabled people are failing to have their basic needs met.

40%
Foreword

Social care is a critical part of daily life for tens of thousands of disabled people. For some, it can mean simply getting out of bed in the morning, making a home-cooked meal, or being able to communicate with friends and family.

Importantly, social care also provides the support disabled people need to live actively and independently: working, studying, or keeping fit.

As Amy told us, it is difficult to overestimate how important this can be:

“It’s about being able to have the same aspirations as others. I hold down a job, live independently and I am able to live life in the way I choose. I believe this is a fundamental right, but it has also given me an immense sense of freedom.”

But when this support is taken away, it can leave disabled adults distraught, alone and in crisis.

Our report reveals shocking new evidence of disabled people failing to be supported to wash, dress, leave the house and communicate with those around them. It shows people withdrawing from society, becoming reliant on friends and family to provide care and support, often driving those relationships to crisis point. Unsurprisingly, levels of stress, anxiety and mental health conditions are rising as a result.

It is clear that a new approach to care and support is long overdue.

In 1948 the National Assistance Act established the National Health Service (NHS) and set out how the state would support the most vulnerable in society. Twenty-two years later the Chronically Sick and Disabled Persons Act of 1970 strengthened that support for some, although many remained without the care they needed.

Since then we have seen 40 years of incremental improvements. But now the care system is on the verge of breakdown. Chronic under-funding and a clear lack of political will has created a system that fails too many disabled people, too often.

We have reached a new watershed.
To its credit, the Government has recognised the crisis and has set out a bold vision for the future, built around independence and wellbeing for all.

But for the vision to become reality we must make decisions based on a proper understanding of everyone who uses the system.

The way Britain has been thinking about social care has been dominated by concerns about the ageing population – it is vital that we also recognise the needs and aspirations of the one in three people who need social care and support who are under 65.

Without such an understanding, the positive vision the Government is aiming for will be undermined.

This report attempts to fill some of these gaps in our understanding.

It sets out how the care crisis is playing out for working age disabled people and paints a vivid picture of the impact on their lives. It provides a detailed, costed solution to the crisis. And it outlines what the Government must do to ensure that we finally have a care system that works for all those who need it.

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Executive summary

Care and support is vital for people of all ages. But the debate on social care funding has been almost exclusively about how the system should respond to the demands of an ageing population.

Important as this debate is, one in three people who use social care services are disabled people of working age (1) whose needs are not always the same as those of older people.

As decisions about social care begin to be taken, with the passage of the Care and Support Bill through Parliament, it is essential that we understand what is distinctive about the needs of working age disabled people.

For the first time, this report provides evidence about the size and level of impact of the social care crisis on working age disabled people. The findings are shocking:

- New research carried out by the Personal Social Services Research Unit (PSSRU) has found that, under proposed Government reforms, at least 105,000 working age disabled people are set to miss out on essential care and support.

- This is because the historic underfunding of care is being exacerbated by cuts to local authority funding and leading councils to remove care and support from all but a minority of those with the seemingly most complex needs. Since 2008, over 90,000 disabled people have lost care and support. The new Care and Support Bill will make this trend Government policy.

- This is already having a major impact on the lives of disabled people and their families. Four in ten are failing to have their basic needs met, and underfunding is turning back the clock on disabled people's independence: nearly half of disabled adults report services aren't supporting them to get out into the community.

- The Government must act now to ensure that disabled people continue to receive the care and support they need. For just 0.2 percent of public expenditure, we can support all disabled people to live independent lives of their own choosing, be able to work and take part in the lives of their communities, and be supported before reaching crisis point.

Chapter one: disabled people falling out of the care system

Proposed social care reforms have focused on the needs of older people, but over 105,000 working age disabled people are set to miss out on vital care and support.

- Social care for working age disabled adults is underfunded by at least £1.2 billion. (2)
- At the same time, the number of disabled adults needing care and support is increasing. In 2010 / 2011, 1.1 million disabled people relied on the social care system, but by 2020 we anticipate that the number of people in need of care will have risen to 1.3 million. (3)
- The squeeze on funding is being exacerbated by cuts to Local Authority budgets. Between 2010 / 2011 and 2014 / 2015, local authority budgets will have shrunk by 28 percent, (4) which will be further compounded by the extra two percent cut announced in the 2012 Autumn Statement. (5)
- These cuts are deeply affecting social care services, forcing councils to reduce the numbers of disabled people who are eligible for free care and support. (6)
- If social care reforms go ahead as planned, new research shows that at least 36,000 working age disabled people may lose the care and support they currently receive. (7) A further 69,000 disabled people will continue to live at crisis point without even a basic level of care.
- This means that if the current reforms go ahead as planned, at least 105,000 working age disabled people are set to miss out on vital care and support.
- The funding crisis is also undermining the quality of care services and holding back the drive towards more personalised and preventative services.
- With continued underfunding and little prospect of investment, councils and service providers will increasingly revert back to more traditional models of service provision, restricting people’s independence and also the Government’s ambitions for the transformation of care.

2 This is equivalent to the increasing expenditure amongst working age adults as estimated in Personal Social Services Research Unit (2013) Implications of setting eligibility criteria for adult social care at moderate needs level: www.scope.org.uk/othercarecrisis
3 Based on estimations in Tables 10 and 11 in Personal Social Services Research Unit (2013) Implications of setting eligibility criteria for adult social care at moderate needs level: www.scope.org.uk/othercarecrisis
7 In theory (as drafted) the new legislation will allow councils to set eligibility at a level lower than the minimum threshold, should they choose to, but experience suggests that this unlikely and will fluctuate with the financial climate.
Chapter two: turning back the clock on disabled people’s independence

The rationing of care and support has already left many disabled people at crisis point – and the negative impact on their lives is growing.

New evidence from our survey (8) shows that disabled adults:

• are failing to have their basic needs met: with nearly four out of ten (36 percent) unable to eat, wash, dress or get out of the house due to underfunded services in their area.

• are withdrawing from society: with nearly half (47 percent) saying the services they receive do not enable them to take part in community life and over one third (34 percent) being unable to work or take part in volunteering or training activities after losing support services.

• are increasingly dependent upon their family: with nearly four in ten (38 percent) seeking support services saying they experienced added stress, strained relationships and overall decline in the wellbeing of friends and family.

• are experiencing isolation, stress and anxiety as a result: with over half (53 percent) saying they felt anxious, isolated, or experienced declining mental health because they had lost care and support services.

Many of those losing out in the system want to take part in society and contribute to the economy but without the right support are forced to withdraw, undermining the contribution they could make.

The impact of these cuts is clear both for disabled people:

“I am in debt with my heating costs, I can’t afford to eat, and so now I have injections four times a year, apparently I’m not getting the vitamins and nutrients to help my body cope with several conditions.” Jeeta

and their families:

“Trying to care for me without the support we need is killing my mum. She’s in agony and emotionally worn out. We’re both terrified about what will happen.” Emma

8 Survey carried out August 2012 see page two for further details.
Chapter three: beyond the crisis for disabled people

A cap on social care costs provides little comfort for working age disabled people. The Government must act now and invest £1.2 billion to ensure it averts deepening this crisis.

- We broadly welcome the Government's acknowledgement of the crisis in care funding, and the main proposals of the Dilnot Commission on the Funding of Care and Support.
- But for too long we have been trying to answer the wrong question for working age disabled people.
- A cap on the lifetime cost of care would help protect the assets of those who have spent a lifetime saving. However, because many younger disabled people have few assets to protect, the cap is of little or no benefit in providing the support they need.
- It is time to ask a different question of our care system. The majority of disabled adults are concerned less with protecting assets than with a simpler, more urgent issue: “how can I get the support that I desperately need?”

The solution

- Disabled people have told us that the most important factor in the funding crisis is whether or not they are eligible for state support, and that rationing of funding is having a devastating impact on their lives.
- To resolve this issue, we must have a realistic threshold at which people become eligible for care. As such, we urge the Government to set the threshold at which people become eligible for care at a lower level than is currently proposed.
- Doing so would provide vital care and support to at least 105,000 working age disabled people in England, who would be enabled to live fulfilling lives, to work, and contribute to their communities.
- Modelling carried out by the PSSRU on behalf of Scope shows that providing this care and support to disabled people will cost just £1.2 billion, or 0.17 percent of public expenditure.
- The Government should ensure that the funding for this lower level of eligibility is ring-fenced, at least for an initial three year period, so that council are able to invest in sustainable support, which prevents the unnecessary escalation of people’s needs and the costs associated with them.

9 For more information see: Personal Social Services Research Unit (2013) Implications of setting eligibility criteria for adult social care at moderate needs level: www.scope.org.uk/othercarecrisis
10 This calculation is based on figures taken from HM Treasury PESA tables 2012, available online here: http://www.hm-treasury.gov.uk/pespub_pesa12.htm
Conclusion

The Care and Support Bill represents a profound opportunity for the Government to provide care and support for all those who need it. After decades of trying, this Government now has a chance to plug some of the historic gaps in the system, prevent rising demand for care and support from hitting wider services, drive forward the progress that has been made over the last 70 years – and finally create a system that works for all those who need it.

The consequences of failing to resolve the crisis, however, will be severe. Already suffering from a lack of care and support, tens of thousands of disabled people will be left to manage alone, unable to live independently, to work and contribute to their communities. Hard fought for improvements to the system will be undone and universal and emergency services will be stretched to breaking point as disabled people urgently seek to replace the support they have lost.

The solution we set out in this report is clear, affordable and essential. Disabled people can wait no longer for a system that works for all. The Government must act now to avert this crisis.
Chapter one: A growing care crisis
Summary

- Social care for working age disabled adults is underfunded by at least £1.2 billion. (11)
- At the same time, the number of people needing care and support is increasing.
- The squeeze on funding is being exacerbated by cuts to council budgets, forcing councils to reduce the numbers of disabled people who are eligible.
- If the current reforms go ahead as planned, at least 105,000 disabled people aged between 18 and 64 years are set to miss out on vital care and support.

Over 105,000 disabled people are set to lose out on vital care and support.

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11 Personal Social Services Research Unit (2013) Implications of setting eligibility criteria for adult social care at moderate needs level: www.scope.org.uk/othercarecrisis
The Government’s vision for care and support is under threat

The Government has set out a new and ambitious vision for the future of care and support in England, with the principles of wellbeing and respect for individual choices and decisions at its heart. The Government rightly aspires to create a system that will enable disabled people throughout our society to participate in and contribute to their local communities.

Disabled people across the country are enthusiastic about the positive impact that such a vision could have on their everyday lives. The draft Care and Support Bill reflects some of the long-held ideas disabled people have about how care and support should be provided and it builds on the principles of independence written into the UN Convention on the Rights of Persons with Disabilities.

But before the law has even been finalised, this vision is under threat.

Based on new research, under the Government’s planned changes we believe 105,000 disabled adults risk not being able to get the essential care and support they need. Cut adrift from the system, they will be left to fend for themselves, unable to do the things many of us take for granted like washing, eating, budgeting and communicating, pushing them further to the fringes of society.

Those who are lucky enough to still get support will struggle to get by with the amount of care they receive. A recent Scope survey of 619 disabled people found that two in five disabled adults thought the system was failing to meet their basic needs like washing, dressing or getting out of the house, and nearly half said the services they received do not enable them to take part in community life. In a recent survey conducted by Sense, almost a third of deafblind respondents needed more care and support than they were receiving. Similarly, two thirds of people responding to a survey by the National Autistic Society said they did not have enough support to meet their needs.

The historic underfunding of care services for disabled adults has caused this crisis, which has been exacerbated by more recent cuts to public spending. To deal with this precarious position, councils have been forced to ration their funds and are, in the main, withdrawing support from all but a small minority of people with more complex needs.

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12 See Part one of the Draft Care & Support Bill [2012]: http://www.dh.gov.uk/health/2012/07/careandsupportbill
15 Personal Social Services Research Unit (2013) Implications of setting eligibility criteria for adult social care at moderate needs level.: www.scope.org.uk/othercarecrisis
17 Bancroft et al. (2012) The way we are: autism in 2012, NAS: London
Underfunding and the rationing of support together are perpetuating the funding crisis facing disabled adults. If the Government does not act, the new legislation could turn this trend into an irreconcilable crisis for disabled adults.

Social care for working age disabled people is drastically underfunded

The scale of underfunding in social care is drastic. Based on research carried out for Scope by the PSSRU we have found that for working age disabled adults, the system is underfunded by at least £1.2 billion. (18) If we include the cost of resolving inadequate levels of care, this underspend is likely to be even higher.

This reflects the small amount we spend on social care as a country. Currently only one percent of public expenditure funds care for working age disabled people; overall in 2011 / 2012 the system accounted for just two percent of public spending. This is much less than we spend on education, transport and pensions. In comparison, NHS spending has risen by around 110 percent since the mid 1990s. (19)

At the same time, the number of people needing social care is rising.

In 2010/11, 1.1 million disabled people relied on the social care system, one third of who are working age disabled people. But by 2020 we anticipate that the number of people in need of care will have risen to 1.3 million, because more children with complex needs are living into adulthood (20) and in our ageing society people are living longer with additional care needs in older age. (21)

Although meeting the growth in older people’s needs is vital, population expansion among younger disabled people is also a key driver in the growing demand for social care. Recent projections (22) have suggested that there will be an average annual increase of between 5.4 percent and 7.9 percent of adults with learning disabilities requiring care between 2009 and 2026.

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18 Personal Social Services Research Unit (2013) Implications of setting eligibility criteria for adult social care at moderate needs level: www.scope.org.uk/othercarecrisis
A recent survey (23) published by the Association of Directors of Adult Social Services (ADASS) found that the largest demographic pressure on local authority budgets is from increased numbers of people with learning disabilities (£168 million).

The pressures on funding from this growth in demand are stark and ADASS has suggested that it would require a real-term increase of at least one percent annually just to continue providing for those currently within the system, let alone account for the increasing numbers in need of care and support. (24)

Austerity has pushed the system to crisis point

The gap between need and spending is increasing even further following the recession. Between 2010 / 2011 and 2014 / 2015, local authority budgets will have shrunk (25) by 28 percent, which will be further compounded by the extra two percent cut announced in the 2012 Autumn Statement. (26)

Since 2008 the number of people using care has fallen by at least 90,000, or one in six of all people using care

24 Spending review analysis – follow the money and it isn't there', Mithran Samuel, Community Care 25.10.10: http://www.communitycare.co.uk/articles/25/10/2010/115665/spending-review-analysis-follow-the-money-and-it-isnt-there.htm
These cuts to council budgets are deeply affecting social care services. The ADASS budget survey found that at least 23 percent of the £1 billion reduction in social care expenditure was due to services cuts, not efficiency savings. (27) The Institute for Fiscal Studies similarly found that between 2009 / 2010 and 2010 / 2011 at least a quarter of councils had cut their social care budgets by nine percent. (28)

Sarah Pickup, the president of the ADASS, recently said (29) that national Government was:

“... trying to see adult social care as an island, and it’s not, it’s in the middle of local government which had its grant cut by 28 percent, and so if you had seen adult social care over here, unaffected by the 28 percent, then perhaps we would have been okay.”

Without an increase in funding, councils will either be forced to further cut social care services, or will need to reduce spending on other services such as housing, bin collections, libraries or road maintenance.

The Government recognises the need for more funding, as shown in the transfer of £2 billion from the Department of Health and NHS budgets in the last Spending Review. But this money is insufficient to fill the gap between demand and current expenditure and because it forms part of the grant (Formula Grant), councils are free to spend it across any services, not just social care.

The impact of this funding squeeze has already been dramatic. In the last year alone, the number of 18 – 64 year olds receiving social care fell by 36,000 – a drop of seven percent. (30) Since 2008 the number of people using care has fallen by at least 90,000, or one in six of all people using care. (31) Overall, there are ten percent less people using care and support services than there were in 2005. (32)

As austerity takes its toll on councils, social care funding is already being stretched to breaking point.
Chapter one: A growing care crisis

Councils are restricting eligibility to support

But as more authorities respond to funding cuts the care system will come under even greater strain.

Many disabled people experience health and social care as one system, yet unlike the health in our NHS, council-funded social care is not free at the point of use.

Instead, in order to get state-funded care and support a person must be assessed as eligible by their council. Currently, eligibility for support is assessed against a framework called Prioritising Need, also referred to as the Fair Access to Care Services criteria (FACS). (33)

Councils can decide where to set the threshold for support, based on the levels of need described in the FACS criteria. This means that whilst councils might assess all of your needs, it is only those that reach the threshold that will be provided with funding and support.

Introduced in 2003 and updated in 2010, (34) the criteria were intended to create a national framework against which councils should set their eligibility policies. FACS is based on the risk and impact faced by an individual if issues relating to their independence are not addressed. The criteria are defined across four bands; ‘low’, ‘moderate’, ‘substantial’ and ‘critical.’ The band a person’s need is assessed as being determines whether or not they will be entitled to care and support.


What are the Fair Access to Care Services (FACS) criteria?

For example, the criteria for an individual assessed as ‘moderate’ are as follows:

- there is, or will be, an inability to carry out several personal care or domestic routines; and / or
- involvement in several aspects of work, education or learning cannot or will not be sustained; and / or
- several social support systems and relationships cannot or will not be sustained; and / or
- several family and other social roles and responsibilities cannot or will not be undertaken.

At present, councils have discretion to set eligibility for care and support at any one of these different levels of need.

Only 24 out of 152 councils provide care to those with moderate needs
Chapter one: A growing care crisis

As social care budgets have tightened, many more councils have made the difficult choice to raise their eligibility thresholds to 'substantial' or above. This means that hundreds of thousands of disabled people are not receiving social care, despite having been assessed as in need. (35)

In 2005, 50 percent of the 152 local authorities in England provided care and support to those with 'moderate' needs and above, but by 2012, 84 percent were only providing services at the higher threshold of 'substantial' needs. (36) This means that only three councils now provide social care to people who fall into all four eligibility bands and only 24 provide care to those with 'moderate' needs and above.

Recent research suggests that the funding pressures on councils coupled with the discretion they have to set eligibility has led to councils using eligibility thresholds to try to manage numbers coming into the care system, rather than focusing on determining levels of support. (37) Increasingly councils are setting their own augmented thresholds of ‘lower critical’ or ‘higher’ or ‘upper’ ‘substantial’ and relying on alternative ways of restricting expenditure. (38)

Worryingly, this rationing and underfunding of care has led to a reduction in early intervention and the prevention of needs escalating. A recent British Red Cross / ComRes poll found almost two thirds (64 percent) of councillors across England have seen funding for preventative and low-level social care cut or frozen since the last local election. (39) Given the focus on preventative care within the Government’s White Paper, (40) there is yet another clear contradiction between the vision and aspirations for social care and the limits placed upon us by the funding crisis.

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35 This has been happening for some time, see for example Leonard Cheshire Disability (2008) Your Money or Your Life: Disabled people’s experiences of the loss of social care services in England: http://www.lcdisability.org/?lid=6966
38 Through for example the use of local Resource Assessment System (RAS) – for a good explanation of these systems see: http://www.supremecourt.gov.uk/decided-cases/docs/UKSC_2011_0005_Judgment.pdf - or attempting to cap care expenditure, for example see ‘Legal challenge launched against council care spending cap’, Mithran Samuel, Community Care, 02.01.13: http://www.communitycare.co.uk/articles/02/01/2013/118798/legal-challenge-launched-against-council-care-spending-cap.htm?cmpid=NLC|SCSC|SCDDB-20130103-GLOB|news
Reduced eligibility means disabled adults will lose out

Although the FACS criteria are intended to be a broadly national framework, councils have considerable leeway over where the threshold for eligibility is set. This has resulted in significant variation across the country and has created a postcode lottery of support.

The Government has rightly recognised the need to resolve this postcode lottery and plans to introduce a national eligibility threshold in the draft Care and Support Bill. This will be a vital step in ensuring more clarity and consistency in the provision of care for disabled people in the England.

However, the Government has indicated that the level of the threshold is most likely to be set at the higher level of ‘substantial.’ We are concerned that the Government is approaching this decision the wrong way round. Instead of starting out by considering what level of care and support would allow people to achieve and contribute to their communities, the likely threshold is being set before the real need, and the real benefits, have been properly understood.

Having a higher threshold for care and support will mean that:

1 Many disabled people will lose the vital support they receive

Research commissioned by Scope from the PSSRU at the London School of Economics and Political Science (LSE) found that there were 36,000 18 – 64 year old disabled people with ‘moderate’ level needs currently receiving social care. Under the Government’s current plans, all of these disabled people are likely to lose out. (41)

Yet because of the widespread raising of eligibility thresholds, there is a second, larger group of working age disabled people who are outside the system and will continue to lose out on support following reforms. The PSSRU research shows that there are at least 69,000 disabled people with ‘moderate’ level needs who are not currently receiving care and support. This number includes disabled adults whose needs are known to councils, but who fail to meet a higher threshold of eligibility. It also includes those who are not fully on the radar of councils, who are in temporary or transitory care in the NHS or are totally reliant on family members for care and support.

This means that at least 105,000 disabled people are set to miss out following the Government’s reforms.

41 In theory (as drafted) the new legislation will allow councils to set eligibility at a level lower than the minimum threshold, should they choose to, but experience suggests that this unlikely and will fluctuate with the financial climate.
Currently many councils are ‘assessing up’ disabled people in order to ensure they continue to get care and support. This exacerbates the postcode lottery, making it very difficult to monitor levels of social care coverage. It also means disabled adults can be significantly dependent on the goodwill of staff to ensure they get the basic care and support they need. The new eligibility framework and national threshold proposed in the draft Bill aims to achieve a more consistent approach.

2 The burden on universal services will significantly increase, but disabled people’s needs still won’t be met:

The Department of Health’s vision is that people who aren’t eligible will be able to find support ‘outside’ the formal, council-funded social care system. (42) This means that disabled people will be forced to rely on any universal and community-based services that may be available.

But cuts to council funding have hit universal services even harder than social care. The Institute for Fiscal Studies found that spending on all central services outside social care and education dropped by more than 12 percent between 2009 / 2010 and 2011 / 2012. (43) As such, universal services are unlikely to be in a position to pick up the unmet need in the social care system. Universal services are also, by definition, general services for everyone, so are not tailored to meet disabled people’s care needs and are often too inflexible to provide appropriate support. Staff who provide these services may also not have the right experience, potentially leading to safeguarding issues.

In short, we are at risk of creating a positive, empowering social care system but one which works only for the very few with the highest level of need. A large group of disabled people, many of whom are keen to contribute to society but lack the right support, are being left to fall out of the system. The consequences of this will be appalling, as this response to the Scope survey shows:

“I was told that I no longer met the criteria... I can dress myself but I’ve had to give up wearing socks. I struggle with shoes and frequently have to ask friends, colleagues, family and even people on the street to rescue my shoes and put them back on when they fall off.” Joshua

3 The quality and transformation of care services will be undermined

Underfunding is having a profound effect on the quality of care services, undermining the drive for more personalised services and adding strain to other publicly funded services. Councils are feeling a tension between providing the care they know disabled people want and need, and delivering just enough care at a sufficient quality in the context of ever reducing budgets.

Social care and support services are being underfunded and overstretched and disabled people have consequently experienced a reduction in the amount of care that they receive. One fifth (20 percent) of people with learning disabilities surveyed by the Learning Disability Coalition in 2011 were told that their hours of care would be reduced.\(^{(44)}\) In a survey conducted by the Care and Support Alliance, more than one fifth (23 percent) of respondents said services had been cut back even though their needs had stayed the same.\(^{(45)}\). As one disabled person told us:

“I used to have a good support worker that was just for me – now she is really stretched and has to key work 3 – 4 others, she now has some management responsibilities – such as supervising all the lower paid staff since the cut backs and has loads of paperwork. I feel that she has not got enough time for me to achieve the things I want and need.” Ira

Over the past two decades in particular, we have seen a transformation in the kind of care that disabled adults receive. \(^{(46)}\) Whilst once the only option was segregated residential units, more recently disabled people have been put into the driving seat, creating more support in their own communities or homes and even taking part in commissioning their own services. \(^{(47)}\)

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\(^{(45)}\) Care and Support Alliance (2011) Evidence to the Commission on the Funding of Care and Support: http://www.carersuk.org/media/k2/attachments/Care_and_Support_Alliance_Evidence_to_Commission.pdf


\(^{(47)}\) For example, a user-driven commissioning programme set up by a consortium of Strategic Partners to the Department of Health in March 2011 (led by Disability Rights UK and Shaping Our Lives), http://www.disabilityrightsuk.org/userdrivencommissioning.pdf
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As well as bringing benefits to disabled people, (48) the co-production of services has also been shown to effectively mitigate the effects of underfunding. When comparing 152 local councils, a report by Demos in 2011 found that involving service users in designing and planning their services, and in some cases delivering them, was among the interventions proven most effective in mitigating the impacts of cuts to council budgets. (49) Many of these newer forms of care have focused on enhancing disabled adults’ independence and their ability to make informed choices about the care and support they receive. (50)

Funding those with ‘moderate’ needs encourages a less crisis-driven approach in social care, guarding against people’s needs escalating unnecessarily (51) and realises savings to health services and the wider economy. In 2011, the Audit Commission found that 70 percent of councils reported efficiencies by using preventative services for adult social care. (52) Modelling by Deloitte commissioned by the British Red Cross, recently demonstrated the cost benefit to health and council services of preventative support. Through the prevention of hospital admission and readmission, reduction of the length of hospital stays and prevention of the use of expensive domiciliary and residential care, it was estimated that in 2012 the British Red Cross, through six community and A&E discharge schemes, realised savings per user from these schemes ranging from £168 to £704. This relates to a rate of return of between 40 percent to 280 percent. (53)

Similarly, the National Audit Office found in their report into the cost of supporting adults with autism that ‘beside the negative impact of such crises on a person’s life, acute services are also expensive, with inpatient mental health care costing between £200 and £300 per day’. They concluded that if local support services identified and supported just four percent of adults with high functioning autism and Asperger syndrome the outlay would become cost neutral over time. (54)

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With continued underfunding and no prospects of investment, councils and service providers will however increasingly revert back to more traditional models of service provision, which will undermine both people’s independence and the wider transformation of care, as well as the Government’s ambition as set out in draft legislation and the Care and Support White Paper. (55) As a disabled person whose care had been reduced told us:

“The social worker said if I couldn’t get 24 hour care in my own home I’d be forced into residential care against my will. I feel suicidal at the thought of losing my home and freedom. My basic human rights are being denied. I’m devastated.” Thomas

Underfunding has already resulted in many younger adults ending up in inappropriate residential care services meant for older people. (56) In 2009, of the 24,000 young adults with physical disabilities living in care homes, it is estimated that around 9,000 were inappropriately housed. (57) A report (58) by Mencap and the Challenging Behaviour Foundation has shown that that placing people in inappropriate services is not only short sighted, but can also negatively affect their wellbeing and often end up costing the tax payer more in the long run: Winterbourne View being a case in point. (59)

In addition, the underfunding and rationing of resources will reinforce the disproportionately poor quality of care and support services that people from black and minority ethnic groups often receive. These groups face difficulties finding services that are culturally appropriate or community-specific. (60) Cultural difference can best be accommodated through small, tailored provision which requires development by local user-led organisations, but under-investment will continue to drastically reduce the likelihood of these sorts of inclusive, locally tailored designs.

56 When the Loving Care Stops, The Telegraph Online, 2 September 2012, Cherrill Hicks, http://www.telegraph.co.uk/health/9515657/When-the-loving-care-stops.html
High eligibility for care will affect a wide range of disabled people

Setting the national eligibility threshold at a higher level of ‘substantial’ would leave many disabled adults disadvantaged. We believe that the proposed social care system will predominantly affect:

1 36,000 disabled adults (61) with ‘moderate’ level needs who are currently receiving just enough care and who risk simply falling out of the social care system under the proposed changes. Their needs are likely to escalate without adequate and appropriate support. This will result in declining health, wellbeing and finances, and increasing cost to the state when they return to the system with a higher level of need and in crisis.

Sarah has a learning disability and lives independently. For several years, she enjoyed going to a local day centre once a week. The council has now stopped funding people with ‘moderate’ needs so Sarah is now stuck at home. (62)

Ian uses a wheelchair. He can manage most aspects of daily living on his own as his flat is wheelchair accessible. He used to be funded for a cleaner to come in once a week, but since his funding has been cut, he relies on his sister to keep his flat clean and do his washing. (63)

2 69,000 disabled adults (64) with ‘moderate’ level needs who are not currently receiving any council-funded care and support because of the continued rationing of services. These people are going without the vital support they need to wash, dress, cook, manage a budget or communicate with those around them.

When Michael was first diagnosed with Multiple Sclerosis, he was unaware that local authorities provide care and support to disabled people. When he did approach his local council, he was turned down on the grounds of no money being available. (65)

61 Based on projections in PSSRU (2013) Implications of setting eligibility criteria for adult social care at ‘moderate’ needs level: www.scope.org.uk/othercarecrisis
62 Based on conversations with disabled people
63 Based on conversations with disabled people
64 Based on projections in PSSRU (2013) Implications of setting eligibility criteria for adult social care at moderate needs level: www.scope.org.uk/othercarecrisis
Mary has seen her friends go through the stress of applying and being turned down and does not want to be made to feel like she is begging from the Government. (66)

“I desperately want someone to help me at bedtime but I can’t begin to start recruiting someone. This isn’t just about money; it’s about knowledge and contacts.” Timothy (67)

It will drastically affect those who just need a little bit of support to prevent them from spiralling into crisis:

Oliver’s health is unstable and precarious. His father has dementia, and Oliver needs someone to man his phone for just a few hours each month in case his father calls in an emergency. Without this support Oliver cannot do his voluntary work, and has resigned from committees on which he used to be a member. Because of the stress from lack of support, Oliver’s physical and mental health problems have been worsening. (68)

3 Even disabled people who are deemed to have ‘substantial’ or ‘critical’ needs and who receive some support from the local authority, find that the services they receive are inadequate. More than two in five of Scope’s survey respondents with ‘substantial’ needs had to spend their own money to get the care and support they fundamentally needed, and 50 percent for those with ‘critical’ needs. This widespread problem will continue to plague a system which sets the national eligibility threshold at ‘substantial’.

Kate has ‘critical’ care and support needs, but she has to make a large financial contribution to her care. This means a lot of her own money is being swallowed up by the cost of additional hours of support above those her council funds. As a result, she does not have the extra money she needs to fund other essentials like maintaining disability equipment or improving the accessibility of her home. (69)
Chapter one: A growing care crisis

This is affecting many disabled people with different conditions and in different situations. This includes, for example:

4 People with a visual impairment, who are already disproportionately feeling the effects of ever-rising eligibility thresholds. The total number of adults recorded as ‘visually impaired’ in receipt of social care services has reduced by 36 percent since 2005 / 2006, whereas in comparison, the total number of adults in receipt of social care services has reduced by 16 percent.

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Tim has a visual impairment. He has received support from the council for several years, but his care package has been reduced. He has been told that if he still wants support with shopping, he will have to pay for it himself. (71)

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5 For disabled people with progressive conditions, being assessed as having ‘moderate’ needs and subsequently being turned down for care will mean the deterioration of their condition. This will introduce perversity into the social care system; with some disabled adults having to wait, and suffer a worsening of their condition, until they are deemed as having ‘substantial’ needs.

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“I have waited almost two years for my broken shower to be adapted... partially due to the council being slow and not believing me when I told them what I needed until they saw me in relapse.” Uma

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6 Setting the national eligibility threshold at ‘substantial’ would also badly affect people with conditions that fluctuate. These people vary between having different levels of need. Because care is becoming ever more tightly rationed this group will only get help if they can consistently demonstrate a substantial need. Some disabled people are assessed as having ‘moderate’ needs on a ‘good day’, but then lack the support they need to keep well or to help them cope during more difficult periods.

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70 Based on an initial analysis of the National Adult Social Care Intelligence Service (NASCIS) Referrals, Assessments and Packages of Care data
71 Survey respondent
Anna has severe bipolar disorder. On the day of her assessment for care and support Anna feels relatively well. To the assessor it appears that Anna only has ‘moderate’ needs, so is not able to get any help from the local authority at all. But on a bad day, Anna’s situation is very different. She is sometimes unable to dress herself, get out of bed, wash, or get out of the house. Anna is unable to work or volunteer.”

Most of the time Matthew needs help with just one or two everyday tasks, and a little help with his work and family life. But Matthew has a fluctuating condition, and because of a reduction in the care and support services he receives, has been bedridden for weeks. (72)

Megan’s council decided they could no longer fund her care and support. Megan’s mental health condition fluctuates drastically, with ‘blocked out’ memories sometimes unexpectedly coming back and having debilitating effects on her day-to-day life. Megan sometimes feels that ending her life is the only option. (73)

Some people with high functioning autism or Asperger syndrome may only need some seemingly low level support, such as help with social skills and managing about the house (e.g. with bills and organising cleaning activities). Frequently, these types of need are not recognised by councils as being ‘substantial’. Yet without this help, this group are at risk of developing more severe problems, such as social isolation and severe mental health problems.

“My son has Asperger syndrome and the local social services said his IQ was normal and so they couldn’t help. They said he could do things like cook and go to the shops. Yet the extreme challenges he faces with communication and social situations led to extreme isolation and resulted in him developing such significant mental health problems that he was later sectioned.” Sandy (74)

In an era of difficult spending choices, there needs to be a way of prioritising who should receive care and support, however setting the threshold at ‘substantial’ will disadvantage many. In the next section we look at how the underfunding and rationing of support is already taking its toll on the lives and finances of disabled people.
Chapter two: Disabled people at crisis point
Summary

Social care cuts are having a serious impact on the daily lives of disabled adults and their families.

Our social care survey (75) reveals some stark realities. We found that disabled adults:

• are failing to have their basic needs met: with four out of ten (36 percent) unable to eat, wash, dress or get out of the house due to underfunded services in their area.

• are withdrawing from society: with nearly half (47 percent) saying the services they received did not enable them to take part in community life and over one third (34 percent) being unable to work or take part in volunteering or training activities after losing support services.

• are increasingly dependent upon their family: with nearly four in ten (38 percent) seeking support services experiencing added stress, strained relationships, and an overall decline in the wellbeing of friends and family.

• are experiencing isolation, stress and anxiety as a result: with over half (53 percent) saying they felt anxious, isolated, or experienced declining mental health because they had lost care and support services.

The picture is shocking, but simple: an ever-rising eligibility threshold is resulting in a drastically poor quality of life for tens of thousands of disabled people.

Two in five disabled people are failing to have their basic needs met

75 In Summer 2012 over 600 disabled adults aged between 18 and 64 took part in our survey and told us about their experiences of care and support in England. All quotes in the report come from the survey and the conversations we have had with people afterwards.
Chapter two: Disabled people at crisis point

Disabled people are not getting their basic needs met

The underfunding and rationing of services has left disabled people without the vital support that they need to meet their basic needs. Four out of ten (36 percent) respondents to our survey said that due to the withdrawal of funding for their support, they were not able to fulfil basic personal care tasks such as washing once a day, getting dressed, eating home-cooked food or getting out of the house. Respondents told us of the indignity they were experiencing:

“I often go without a shower or for days without using catheters as I just don’t have the energy to manage.” Michelle

Disabled people’s living conditions can also quickly deteriorate without practical help. (76)

“Cleaning surfaces, appliances, cupboards, washing floors, tidying, dusting etc., are no longer getting done. So my home is becoming increasingly unhygienic and, perhaps, potentially hazardous to myself and to visitors. I cannot afford to replace household appliances such as my fridge-freezer (which has rotting, rusted doors and leaks puddles of water onto the floor).” Sohail

Councils are being forced to make difficult decisions about people’s care. Even when disabled people do receive care and support, cases of inappropriate or inadequate care are becoming increasingly common. One respondent told us:

“I am worried about my health, my dignity, my privacy and my skin if I am forced to wear incontinence pads instead of getting help to go to the loo.” Charlie

The problem is worse for those with ‘moderate’ care needs. 41 percent of respondents to our survey who had ‘moderate’ needs said that the services they receive from the council did not meet their basic needs, compared with 17 percent for those with ‘critical’ needs and 18 percent for those with ‘substantial’ needs. Disabled people denied social care services are being picked up by other, more expensive services when their situation deteriorates. (77)

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Many disabled people are withdrawing from society

Without the care and support they need, tens of thousands of people who are ready and willing to participate and contribute to society and the economy, are instead isolated from their local communities. A relatively small amount of support can make all the difference between independence and isolation. (78)

Nearly half (47 percent) of respondents to our survey said the services they received did not enable them to take part in community life – by which we mean participating in local organisations, socialising with their friends in the local area or going to events in the community. (79) Again, the care and support system is hitting those with ‘moderate’ needs the hardest. Nearly two thirds (64 percent) of survey respondents with ‘moderate’ needs said that their care services did not help them partake in community life, compared with 23 percent for those with ‘critical’ needs and 27 percent for those with ‘substantial’ needs.

“I don’t do paid work but was doing voluntary work but have been resigning from committees because I just can’t cope. This is my precious tenuous link with my community going up the spout.” Alannah

One respondent who needs care and support to get out of their house and into the community told Scope:

“Many activities I would like to attend are at weekends and I only have help getting up on weekdays, so I miss such concerts, festivals etc.” Geoff


79 Where engaging with the community refers to activities that bring the disabled person outside of his / her house, going to a place of worship, voting in elections, using local leisure centres and parks, taking part in community events or volunteering.
For many it is impossible to find and keep a job

A huge number of disabled people are also unable to find and keep work. Disabled people told us that their care and support was a critical factor in the working life. Without it, many reported being unable to sustain work or meaningfully engage in work related activity. Over one third (34 percent) of respondents to our survey who had lost their care and support services were unable to work or take part in volunteering or training activities. This reflects research by the National Autistic Society, which shows that that just 15 percent of people with an autism spectrum condition are in full-time employment with a lack of adequate support being a key barrier. (80)

Respondents also told us about how a lack of care is making sustained employment almost impossible:

“They claimed I was no longer was eligible for the (social care) services despite medical evidence to the contrary. A Local Government Ombudsman complaint followed. Finally I am being reassessed... It has reduced the quality of my life and impacted upon my ability to work. My job is now in jeopardy as I have been off sick for one year.” Katherine

1 in 3

One in three people who have lost their care package are unable to work

Others told us they have a strong disincentive to engage in paid work or accumulate savings because under existing care rules once they own over £23,250 in savings or assets (81) they become liable for the cost of their support. This results in many disabled adults having to weigh up their career prospects with the risk of exceeding the mean-tested threshold and not having enough money to pay for their own care needs. As one respondent put it:

“Even though I do work full-time I do not feel incentivised as I am turned down for grants for extra equipment I may require because of means testing. There is also no incentive to save because it will inevitably be taken from me for care I require in the future. [The care system] makes it seem like it is best to spend and have more help from the state. It’s wrong but true. I have a spread-sheet of income and expenditures to make sure I am living within my means, even with my care costs. I feel driven to progress so I can earn well... not all feel this though.” Ben (82)

Needless to say, inadequate social care for working age disabled people is a contributory factor in the reported failure of wider Government agendas, such as the Work Programme and Work Choice, in getting substantive numbers of unemployed disabled people back into work. (83)

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82 Respondent to the Scope Money Matters Survey 2010

83 Only 1 in 50 disabled people on the scheme have been supported into work and only 1 in 100 Employment and Support Allowance (ESA) claimants found a job. Of 878,000 people referred onto the scheme, only 31,000 have successfully found work, see: http://research.dwp.gov.uk/asd/asd5/report_abstracts/rr_abstracts/rra_821.asp
Lack of social care also removes from the economy the many family members who have to take on informal and unpaid care roles as a consequence. The 2011 Census found that one in ten (10 percent) residents of England and Wales (5.8 million people) devote at least part of their week to providing care without any expectation of payment. (84) Informal carers are less likely to be employed or be in training or education than non-carers. For male informal carers, 68 percent are in employment compared to 82 percent of men with no caring responsibilities. For female informal carers, only 56 percent are in employment compared to 66 percent of women with no caring responsibilities. (85)

One respondent, who was told that they were ineligible for support from their council, told us:

“My husband has been unable to continue with his job as he has to care for me to enable me to work to pay for the additional needs that I have. This has had a huge financial impact on our lives and left us with debt.” Amanda

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**1 in 10**

One in ten people provide unpaid care

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Lack of care and support is forcing disabled people into debt

A lack of support is forcing many disabled adults into debt. Some are forced to sacrifice spending on everyday essentials. As one respondent told us:

“I am in debt with my heating costs, I can’t afford to eat, and so now I have injections four times a year, apparently I’m not getting the vitamins and nutrients to help my body cope with several conditions.” Jeeta

Disabled people who are no longer deemed eligible for state support are being forced to pay the full costs of their own care and those who receive insufficient care are ‘topping-up’ using their own money. Nearly two thirds (63 percent) of survey respondents with ‘moderate’ needs had to spend their own money to get the care and support they fundamentally needed, compared with only 43 percent for those with ‘substantial’ needs and 50 percent for those with ‘critical’ needs. This helps to show that the vast majority of those with ‘moderate’ needs – increasingly deemed ineligible for support – are not being effectively picked up by universal services, but are likely to pay for their own care, often causing financial instability. Many will be left without any support altogether.

“We have a lot less money... have had to dig into savings and can’t afford to mend the roof which is leaking and getting worse.” Kim

Over one third (34 percent) of survey respondents reported experiencing debt, regularly having to borrow money, re-mortgaging their home or having to go without essential equipment. One person had accumulated £20,000 worth of debt and could no longer afford to pay for their carers, leaving them with insufficient support.
This is of real concern as disabled people are already more likely to experience financial hardship. Disabled people have significantly lower annual earnings (86) – one in three (31 percent) living in low income households (87) and more than 40 percent lacking formal savings. (88)

Disabled adults funding their own care are likely to be hit by cuts and changes to disability benefits. Disability Living Allowance (DLA) – and the new Personal Independence Payment (PIP) that is replacing it in April 2013 – is a payment made to disabled people to help them meet the significant additional utility, transport and other costs that arise from their disability. (89) The care crisis is forcing disabled people and councils to use this money to contribute towards the cost of their care. In 2011 all but four councils (90) took at least one care component of a person’s Disability Living Allowance (91) into account when assessing their care contributions. The £1.2 billion worth of cuts the Government has made to the DLA budget (92) will therefore affect those using them to partially or fully fund their own support and exacerbate the crisis.

86 In a typical 9 to 5 job, disabled people would earn £2,000 less each year than non disabled adults. ODI disability equality indicator B7: http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php
88 Scope (forthcoming) Financial Inclusion for Disabled People
90 Cornwall, Kingston upon Thames, Newham and Plymouth
91 Disability Living Allowance is a payment which is awarded to disabled people to help them meet the extra costs arising from their disability. For more information see the Government website: https://www.gov.uk/dla-disability-living-allowance-benefit/what-youll-get
Chapter two: Disabled people at crisis point

All of these factors leave disabled people in a state of severe financial instability, making them more vulnerable to changes in their circumstances or condition. This particularly affects the many disabled people with fluctuating or long term conditions who are currently being assessed as ineligible for care and support. (93) This problem will affect more people if the national threshold is set at ‘substantial’.

Failure to get care is affecting disabled people’s mental and physical wellbeing

With unmet needs, family strains, exclusion from communities, and unemployment and consequent social isolation and financial hardship, the current social care system is having a profoundly negative effect on the wellbeing of many disabled people.

A third (33 percent) of adults with autism responding to the National Autistic Society’s 2008 survey said they had developed serious mental health conditions as a result of a lack of support. (94) In 2012, over half (53 percent) of respondents to Scope’s survey said they felt anxious, isolated, or experienced declining mental health because they had lost care and support services.

“My repeated failure to obtain due support from those with the power to provide this, has made me feel rejected, excluded, worthless, irrelevant and of no value to society. The resultant abysmally poor quality of life and standard of living I have to endure has caused me permanent damage and injury to my wellbeing, over and above the injuries sustained through no fault of my own, at the time of the road-rage attack and its aftermath. I have lost much of my self-respect and confidence.” Martin

“I have got stressed and it has badly affected my condition.” Martha

“I am constantly worried that we’ll either end up in prison for not paying tax or in a care home.” Stacy

The widespread mental and physical effects of a lack of care and support threaten to undermine further the Government’s vision for wellbeing to be at the heart of these reforms.


Disabled people’s families are under strain

Because disabled people are less able to rely on state-funded services and have little money and few assets themselves, they have to depend more on family members for care and support. Nationally, the number of UK residents giving 20 or more hours of unpaid care a week for someone with an illness or disability has increased by five percent between 2001 and 2011. (95) As respondents to our survey made clear, these new family dynamics are putting significant strain on the relationships they hold most dear, leaving disabled people feeling guilty and like a burden on their loved ones.

“My husband works 40 hours a week as well as looking after me. I don’t like the fact he does as much as he does. He is my husband not my carer.” Jane

One in five (20 percent) of respondents to our survey felt that they were being forced to become more reliant on their friends and family. Nearly four in ten (38 percent) who sought care and support services from their local council experienced added stress, strained relationships, and overall decline in the wellbeing of friends and family. This increased dependence affects those providing informal care. One told us that:

“Trying to care for me without the support we need is killing my mum. She’s in agony and emotionally worn out. We’re both terrified about what will happen.” Emma

There are approximately 55,000 (40,000-70,000) children and young people providing informal care to a co-resident adult in England.

There are approximately 40,000 (25,000-55,000) adults aged between 19 and 64 receiving co-resident care from children and young people in England.

Informal or unpaid care is defined in these data sources in broadly similar terms to mean provision of help or support to family members, friends or neighbours because of long-term physical or mental ill-health or disability or problems relating to old age.” (96)

95 In 2011, over a third (37 percent) or 2.1million of the 5.8million usual residents in care roles were giving 20 or more hours of unpaid care for someone with an illness or disability a week. This marks a five percent increase on 2001 (32 percent, 1.7 million). Office for National Statistics (2011) Census, http://www.ons.gov.uk/ons/re/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/stb-2011-census-key-statistics-for-england-and-wales.html#tab--- Provision-of-unpaid-care
Another respondent told us:

“My son has probably suffered the most; we used to have carers in the morning, probably my worst time of day to help with breakfast etc. At six years old it fell on him to prepare breakfast and get himself ready for school. Now at 8 he often misses school through pretending to be ill because he is worried about me – he should be a child while grownups worry about adult things.” Lotty

Young people in informal care roles are also disproportionately likely to be unemployed. In a study conducted in 2011, out of a sample of 1,985 informal carers, none of the carers under 25 were employed. (97) The average caring duration for younger carers was just over two years which indicates a considerable on-going commitment that is highly likely to impact on their future employment opportunities. (98)

We need to move beyond this crisis

As it currently stands, many disabled people are finding alternative sources for their care and support; putting together a patchwork of support using a combination of friends, family and privately purchased services. Not only does this put incredible strain on their finances and relationships, and drastically reduces the choices and opportunities of those who find themselves in informal care roles, these ‘solutions’ are extremely fragile. They are likely to unravel at the times they are most needed. (99)

97 Compare this with the fact that in 2010, The unemployment rate for 16-25 year olds nationally was 20 percent. The Poverty Site (2011) Young adult unemployment, http://www.poverty.org.uk/35/index.shtml


Chapter three: Beyond the crisis
Summary

• The social care system is chronically underfunded, leading to a rationing of support which is profoundly affecting disabled people’s lives.

• Too many decisions about the future of social care have been made without a full understanding of the needs and aspirations of younger disabled adults.

• For working age disabled people a cap on care costs provides at best only part of the answer.

• Instead, the most critical part of social care reform is the level at which we set the eligibility threshold.

• We strongly recommend that the threshold is set at ‘moderate’ or the equivalent level, with the necessary funding being made available to support this.

• New evidence shows that setting the threshold at ‘moderate’ will cost £1.2 billion, and will ensure that hundreds of thousands of working age disabled people receive the care they urgently need.

0.17% of public expenditure will resolve the crisis for working age disabled people
Chapter three: Beyond the crisis

The care system is failing working age disabled people

Increasing demand and underfunding have pushed our care system to crisis point. The impact on disabled people’s lives is severe, with too many being refused social care, and even more receiving inadequate or inappropriate services.

Some clear messages are emerging from our analysis in the previous chapters of this report. Disabled adults need, and want, a funding solution that addresses the:

- Demographic changes and increasing demand for care and support;
- Chronic and historic underfunding of care;
- Escalating rationing of care funds and services;
- Unnecessary and damaging escalation of need.

Putting disabled adults back into the solution

There is widespread agreement that investment has to be made in social care to make it fairer and more sustainable for the future. (100) But governments of all colours have not invested enough time and thought into understanding what funding envelope is needed for disabled adults of working age. They have failed to grasp the scale of both met and unmet need in England and have not worked out the cost of ensuring all those who needed care received the support they required.

Through this report, we aim to put disabled people’s needs back into the frame, so that any future solution works for them as well as our older population.

A cap on social care costs alone will not solve this crisis

The funding solution that has taken up the most air time has been the idea of a cap on the amount of money people have to pay towards their care. The cap aims to address the ongoing concern and anxiety that people have about having to use all their savings or assets (like their house) to pay for spiralling care home costs. (101) Late last year, it was reported (102) that the Prime Minister and Deputy Prime Minister had agreed on proposals to cap an individual’s lifetime contribution, as recommended by an independent commission. (103)

101 ‘Care bills will soak up most of our savings’ Rowena Mason, Telegraph, 02.09.12: http://www.telegraph.co.uk/news/uknews/9652629/Care-bills-will-soak-up-most-of-our-savings.html
102 ‘Coalition plan for £75,000 cap on elderly care bills’ Tim Ross, Telegraph, 27.09.12: http://www.telegraph.co.uk/news/politics/9707151/Coalition-plan-for-75000-cap-on-elderly-care-bills.html – the article suggests that the cap could be set at around £75,000, higher than the £35,000 recommended by the Dilnot Commission
Although this is a cautious step in the right direction for older people who may need care later on in life, (104) it does not answer the right question to resolve the crisis facing working age disabled people (or indeed many older people).

A cap on the cost of care is about how to protect the assets and savings of older people who have spent their life accumulating them (105) – but this answers the wrong question for most working age disabled adults.

It is important here to recognise the differences between people who enter adulthood with an impairment and those who acquire an impairment during their working life. For those disabled people whose impairment develops in childhood, they will have little or no opportunity to develop savings and assets, so the cap and costs will be virtually irrelevant as a way of meeting their needs. For this group, Andrew Dilnot, the Chair of an independent commission on care funding, recognised that the cap is only of limited use and importantly recommended that in the future: (106)

‘Those reaching adulthood with [already] eligible care needs will not have had an opportunity to make contributions so [should] receive free, state-funded care’

The second group of disabled adults are those who acquire an impairment during their working lives, so could reasonably be expected to have acquired some savings or assets. The Dilnot Commission suggested that after a certain age this group can be expected to have enough savings to pay a small incremental amount towards the full cap that applies to older people. (107)

However, this group are also unlikely to benefit from the introduction of the cap, primarily because acquiring an impairment has a significantly detrimental impact on income, savings and job prospects. For instance, forthcoming Scope / Ipsos Mori research shows that 85 percent of working age disabled people have not saved any money in the last 12 months because of the extra costs they face (such as having to pay for private transport or higher utilities). This places a huge drain on their resources. So because disabled people have few assets to protect, the tapered amounts would have to be substantially lower than those currently being suggested for older people.

104 ‘PM to Announce Cap on Care Costs’ Age UK, 16.08.12: http://www.ageuk.org.uk/latest-news/archive/pm-to-announce-cap-on-care-costs
105 Those who don’t have any savings or assets would be eligible for a mean-tested support.
There is also a serious debate to be had about the age at which a cap could apply to working age adults and when they might be expected to start contributing to costs of their care. The Commission suggested 40 years of age, but this is without medical evidence to suggest that this is an age at which lifelong conditions are apparent, nor any economic modelling to estimate that by this age most people will have been able to grow the savings they would need to reasonably contribute towards the cost of care.

To make the cap work on both a practical and economic level we would need to re-open this debate to consider whether these expectations are realistic, whether 40 is too young an age and most importantly what the impact of any contribution would be on the lives and finances of disabled adults.

**Where eligibility is set is the crucial question**

For the hundreds of thousands of disabled adults in need of care and support the critical question is not how high a cap on care costs should be, but whether their needs are even deemed eligible for support.

For those who do not meet the eligibility threshold, the cap will not apply, and they will continue to need to meet the cost of their own care. This means that someone whose level of need is not eligible for support, will be expected to pay the full cost of their care, irrespective of the personal and financial costs, even if this runs into the tens of thousands of pounds over their lifetime.

If you are not assessed as being eligible for support, anything you pay towards your care and support will not be recognised by the state as paying towards a cap on the cost of your care.

Similarly, those whose needs are initially seen as ineligible, but escalate in later adulthood due to a change in their condition or as a consequence of lack of support, will have to start paying towards the cap from scratch. The state will not recognise the money that has already been paid out to meet care needs, nor will it acknowledge the continued strain this will put on their finances and the finances of their family.

**This is not only unfair, but it hits working age disabled adults the hardest.**

It hits them once by not recognising their needs as eligible, twice for forcing them to pay towards their care without state recognition and a third time by depriving them of the opportunity to build the savings they would need to contribute towards their own care.

It also could act as a savings disincentive to younger disabled people with, for example, a genetic degenerative condition that is likely to escalate in later working life, as the bulk of any money they save would have to be paid towards this cap.
This brings us back to the core issue of ensuring disabled adults are given equal weight in the reform of social care. The funding question disabled adults are asking is very different to that of older people with assets.

It is not a question of protecting assets and savings, but rather of ‘how do I get the support I desperately need?’ This is why eligibility is the most important aspect of care for disabled adults: it determines who will, and who will not, get state support. Who will, and who will not, be able to dress themselves or cook a healthy meal. Who will, and will not, be able to take up a job.

Setting the eligibility threshold at the right level is crucial for disabled people to get the support they need and to address the crisis in care. If the Government is to meet their own ambitions for a social care system of the future, as contained in the very first clause of the draft Care and Support Bill, the level at which the eligibility threshold is set is also absolutely critical.

**Setting a high eligibility threshold risks deepening the crisis**

Disabled people have told us that the most important factor in the funding crisis is whether or not they are eligible for state support and that rationing of funding is having a devastating impact on their lives.

To their credit, the Dilnot commission (108) and the Government (109) concluded that a national eligibility threshold should be established. But as we have said previously, both got it wrong about where to set it, suggesting that at present, the threshold should be at a ‘substantial’ level of need.

We believe that this is a serious mistake.

This suggestion was made only on the basis of chronic underfunding and ever-increasing rationing of funds and failed to consider the alternatives and the impact on disabled people’s lives.

By contrast, a ‘moderate’ level eligibility threshold would ensure that at least 105,000 people in England (110) get the support they need to wash, dress, eat, communicate and participate.

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110 For more information see PSSRU (2013) Implications of setting eligibility criteria for adult social care at ‘moderate’ needs level: www.scope.org.uk/othercarecrisis
This group comprises:

- 69,000 disabled people with ‘moderate’ level needs who have already lost their support or were outside of the system;

- 36,000 disabled people with ‘moderate needs’ currently in the system who will lose out if the current changes go through as proposed;

- It also includes 8,000 disabled people with ‘substantial’ needs who would be brought into the system as a result of equalising the threshold nationally, which will resolve the postcode lottery and reduce the need for councils to use discretion to assess people up a band and to ensure that they get the care and support that they need.

Setting the threshold at ‘moderate’ would also support an additional 170,000 older people with ‘moderate’ care needs, and 14,000 older people with substantial or critical care needs, as well as retaining care for the 65,000 older people currently assessed as having ‘moderate’ care needs.

This means that in total, setting the threshold at ‘moderate’ would ensure that nearly 362,000 people would receive the vital care and support they require.

This realistic threshold of ‘moderate’ eligibility should apply to both the interim measures and long-term reforms.

As outlined in the Caring for our Future White Paper, (111) the Government is proposing an interim solution to the question of eligibility. Regulations accompanying the draft Care and Support Bill will establish a national minimum threshold which all local authorities must adopt. We are clear that even in the interim the threshold should be set at ‘moderate’.

The Department of Health is also looking at a longer-term framework for assessment and eligibility for social care. Within these new structures too, it is imperative that the threshold for eligibility be set at the equivalent of the current ‘moderate’ level.

We also recommend that the funding to support the needs of people with ‘moderate’ and higher levels of needs should be ring-fenced, at least for an initial three year period. Whilst we acknowledge the Government’s ongoing commitment to localism and councils’ prerogative to allocate funds to other local priorities, a ring-fencing of the funding would ensure that councils, all of whom are experiencing significant pressures in their adult social care budgets, are enabled to prioritise meeting ‘moderate’ levels of needs and thus effectively prevent the escalation of people’s needs and costs associated with them.

Finally, to ensure that disabled adults are incentivised to save, work and participate in our economy, we agree with Andrew Dilnot (112) that the national threshold of eligibility should be supported by a higher means-tested threshold; raising it from the current level of £23,250 to £100,000. This would ensure people of all ages who are eligible for care are not forced to spend their limited savings in meeting the full cost of their care.

**Setting a lower eligibility threshold is affordable and crucial to end the crisis**

Experts at PSSRU at LSE were commissioned by Scope to look at the cost of setting eligibility at a ‘moderate’ or equivalent level. This work estimates that this solution is affordable, with the costs being:

- Approximately £700 million (113) to include disabled adults with ‘moderate’ needs who aren’t currently receiving social care;
- Approximately £378 million (114) to continue providing care to disabled people with ‘moderate’ needs already in the system, who would lose out if the threshold is set at ‘substantial’;
- Approximately £120 million to provide care for people with ‘substantial’ and ‘critical’ needs (115) who currently aren’t receiving care or support, who will be brought into the system as a result of the ‘substantial’ threshold anyway.

This means that the total cost of setting the eligibility threshold at ‘moderate’ for working age disabled people will be £1.2 billion or 0.17 percent of public expenditure in addition to current spending on social care. Our projections show that this is set to rise by a stable rate to £1.4 billion by 2020. (116)

For older people, PSSRU estimates that the net cost of a ‘moderate’ level threshold will be £1.6 billion or 0.23 percent of public expenditure.

This means providing care to all people (both disabled adults and older people) with ‘moderate’ needs and above would cost £2.8 billion on top of the planned reforms or an increase in public expenditure of just 0.4 percent.

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£1.2 billion

Social care for working age disabled adults is under-funded by at least £1.2 billion

For this cost the Government could:

• Provide urgently needed care and support to over 362,000 people

• Ensure that needs are met early, preventing escalation of needs and reducing the burden on services for more expensive, higher levels of need

• Reduce the escalating rationing of care funds and services which we have shown is having a hugely detrimental impact on disabled people's lives

• Finally provide a solution to the chronic and historic underfunding of care which successive Governments have failed to resolve.

The ambition to create a social care system that supports working age disabled people to live independent and fulfilling lives is already contained in the draft Care and Support Bill. But it is going to take political will to turn this ambition into reality. At a time of austerity, the easy option is to let underfunding continue and for councils to continue to be forced to ration the little resources they have for adult social care. But for the hundreds of thousands of disabled people for whom social care provides a lifeline, they need and want to contribute to society and the economy. Failure to act is simply not an option.
Conclusion

Addressing the care crisis must be a priority for 2013 and beyond.

Social care is a big issue for everyone: for central governments, local councils, people using services and their friends and family. When it is discussed, it is usually in relation to the increasing number of older people. It is less well-known that a third of all people using social care services are working age disabled people, so we hope that this report has helped to increase our understanding of the social care landscape from their perspective.

We have outlined a bleak picture of a system which is underfunded by at least £1.2 billion, that is being pushed further to crisis point, due to increasing demand, rising costs and austerity-led budget cuts.

Breakdown in the system causes breakdown in disabled people’s daily lives. Responses to Scope’s survey demonstrate the devastating impacts which disabled people face every day. Underfunding and other serious shortcomings are forcing disabled people to make impossible decisions about whether they can afford to eat properly or get washed and dressed. These are not lifestyle extras, but basic ‘choices’ which disabled people living in the 21st century should never have to make.

The Government has acknowledged that the system is failing and has set out a bold new vision for the future of social care. This is built around promoting individual choice, wellbeing and support which meets a person’s basic needs and importantly enables them to undertake work, education and volunteering opportunities and to participate in family life and contribute to their local communities.

Crucially, although the Government attempts to address the postcode lottery of care through a national threshold; the likely decision to set the eligibility level at ‘substantial’ is flawed. It is unacceptable that over 105,000 working age disabled people are set to miss out as anticipated under the current plans.
Without timely and appropriate support, this laudable vision will remain just that – hollow words on paper with little resonance or reality in the lives of disabled people across the country. Fulfilling this ambition largely depends on where the national eligibility threshold is set.

We believe that it is imperative to set the national eligibility threshold at ‘moderate’ or its equivalent, with sufficient funding to underpin it. We have set out some economic arguments for doing so. Our projections suggest that the estimated total net cost of providing free care to all working age disabled adults at ‘moderate’ level and above is £7.5 billion or one percent of public expenditure. Although this means a small increase in social care spending, we believe that this an affordable and essential way forward. Adopting this course of action would bring about significant benefits to the lives of individuals, their families and wider society. It also has the potential to considerably reduce costs to emergency, health and other community services in the longer term.

Final comments

The reform of social care is a complex subject and adequate funding is the crucial element, which underpins and determines the extent of change that can be achieved. But we realise that it is not the whole story.

Radical reform of assessment processes and structures is urgently required and is currently being considered by the Government. It is essential that additional funding is accompanied by improvements in the design, quality and delivery of services and in the recruitment and on-going training of a suitably skilled social care workforce.

It should also be a catalyst for the changing dynamic between ‘professionals’ and ‘disabled people’ – where people using services have a greater influence over the commissioning, production and evaluation of provision.

These are subjects that we have only touched on in this report, but that merit further consideration in their own right.
Five leading disability charities have come together to urge the Government to end the social care crisis. Through our shared experience of supporting hundreds of thousands of disabled people, we have seen the care system fail too many, too often.

The debate surrounding the reform of our care system has focused on the impact of an ageing population, overlooking the many thousands of younger disabled people in need of care and support. This report is about making sure we address the whole of the care crisis, so that both disabled adults and older people get the care and support they need.

Tell us if you’d like this information to be bigger, spoken or using different colours... Just ask us on 0808 800 3333.